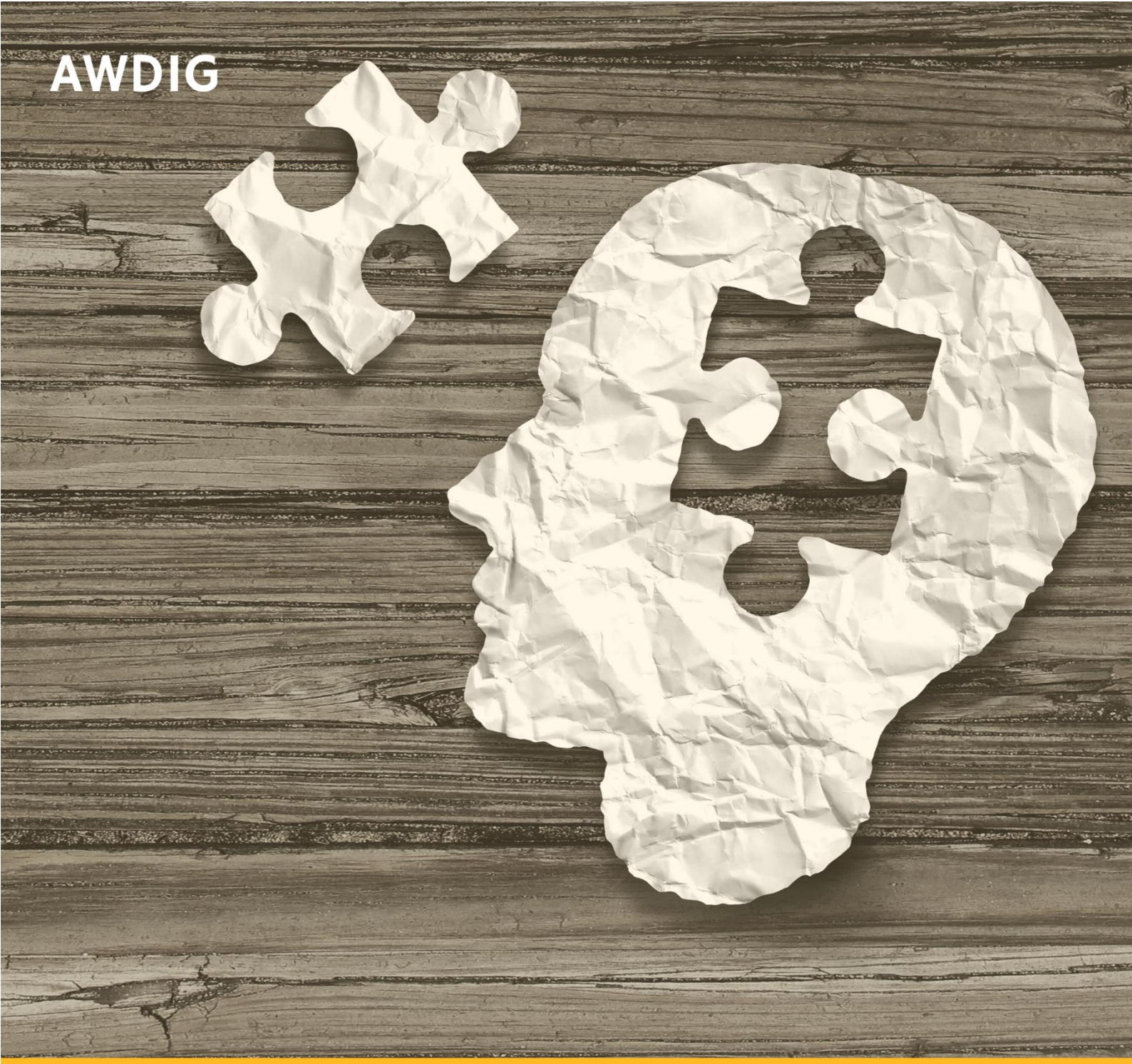
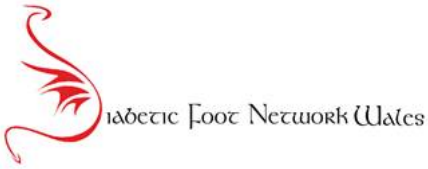
AWDIG



From missing to mainstream

A values based action plan for Diabetes Psychology in Wales

Endorsing Agencies



This document was commissioned by the All Wales Diabetes Implementation Group to lay out recommendations for development of best practice in psychological care within adult diabetes services.

Published 2022 by the All Wales Diabetes Implementation Group (NHS Wales)

Table of Contents

Introduction

Our vision

This document represents a commitment to ensuring that people living with diabetes (PLWD) in Wales are supported to have the best possible health outcomes; physically, socially and psychologically, for the whole of their lives. Our vision is of holistic diabetes services that can cater to all aspects of a person's needs; where people will be able to easily and quickly access specialist care, and of services that actively improve psychological health at every opportunity.

Given the additional burdens that PLWD face across their lifespan, the negative impacts that these burdens have on psychological health, and the complexities that diabetes can add to psychological and cognitive issues, we believe that embedding psychological care into diabetes services is a fundamental requirement if optimal diabetes and general health outcomes are to ever be achieved. We propose to do this by ensuring all that all national diabetes service developments factor psychological health into their planning, that diabetes services promote psychological wellbeing and provide resources to support psychological wellbeing, and that there is a sufficient diabetes psychology workforce across Wales to provide direct input, training and supervision for the entire diabetes healthcare system.

Background

Living with any chronic physical health condition puts additional stress on to the person and those around them, which in turn worsens their physical health outcomes (Moussavi, 2007). Diabetes is no exception to this. Whether it is changing dietary habits, monitoring blood glucose, injecting insulin, or worrying about the future, diabetes and the burdens it brings can intrude into almost every aspect of a person's life. People with type 1 diabetes have to make over 100 additional decisions every single day – the cognitive and psychological load of dealing with this on a daily basis cannot be underestimated.

The evidence that PLWD experience higher levels of psychological distress than people without diabetes is clear and robust (Diabetes UK, 2019). Studies consistently demonstrate that PLWD report higher levels of psychological issues such as depression (Rotella, 2013) and that rates of depression are higher in people living with type 1 diabetes than in people with type 2 diabetes (Elamoshy, 2018). In addition, PLWD regularly face psychological harms specific to living with diabetes. These may include issues such as diabetes distress (Polonsky, 2005), which is distinct from depression (Snoek, 2015), and Type 1 Disordered Eating (T1DE), involving the deliberate omission or manipulation of insulin for the purposes of weight loss (Partridge, 2020). Hypoglycameia can also have a negative effect on psychological health where people have experienced severe episodes (Chatwin, 2021), or where they have lost their hypoglycaemia awareness. High levels of psychological distress and diagnosable psychological disorders are consistently observed in individuals with a pattern of repeat diabetic ketoacidosis admissions (Allcock, 2020), with young adults being at particularly high risk (GIRFT - Getting It Right First Time, 2020). There is also a significant need to develop support for PLWD and dementia, particularly as adults with diabetes are at higher risk of developing dementia early in life (Zheng, 2021). In effect, there is evidence for the need for psychological support for people living with diabetes at all stages of their lifespan, and at all levels of intervention.

Links between increased psychological distress and worsening diabetes self-management are also well established, with high diabetes distress predicting higher average blood glucose levels (as measured by HbA1c) in both people with type 1 (Hessler, 2017) and type 2 diabetes (Fisher, 2010). Despite this, access to appropriate psychological support for adults living with diabetes in Wales and the wider UK has traditionally been a missing component of NHS care, due in part to the ongoing gaps between physical and psychological health services. The vast majority of practitioners working in generic mental health services will have no expertise in either the assessment or the management of diabetes specific issues. This can reduce the likelihood of PLWD wanting to engage with support unless they reach a crisis point, can undermine the efficacy of interventions for PLWD, and in some circumstances can lead to significant risks being missed (e.g. the use of insulin as a means to self-harm or to enable a suicidal person to end their life). Further, the communication gaps between mental and physical health services mean that there is often a misperception that mental health services are adequately trained and provisioned to meet the needs of people living with diabetes, when the experience of PLWD who have used those services indicates that this is very rarely the case (Diabetes UK, 2019).

As well as causing significant distress and adverse health outcomes for the person, unmet psychological need in PLWD has multiple negative effects on the system around the person, including their family, their employers, and the healthcare system (figure 1). This is an issue that services simply cannot afford to ignore.

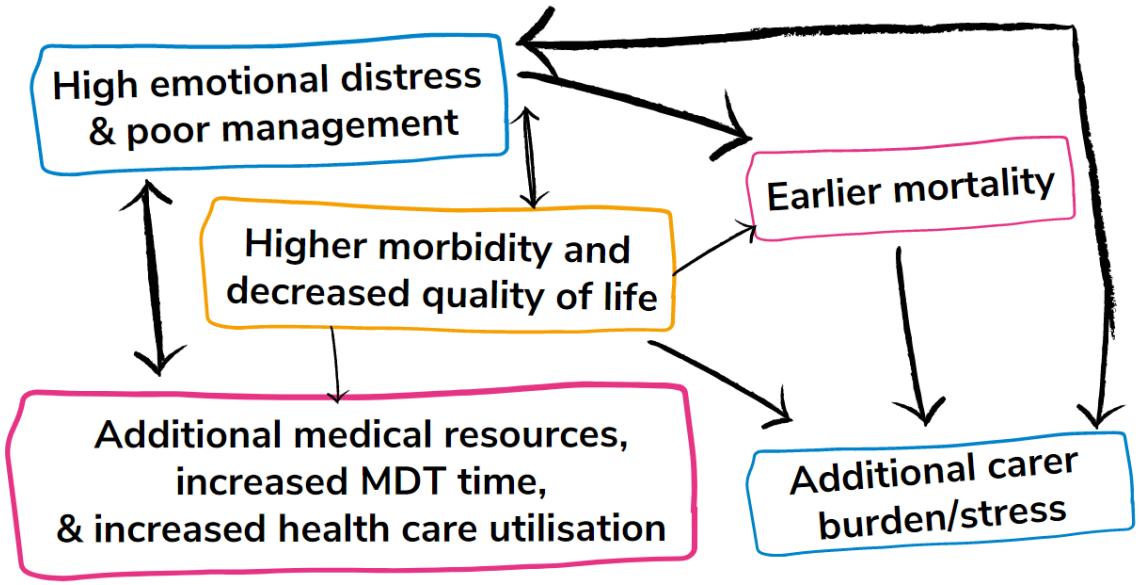


Figure 1 - Impact of unmet psychological need in people with long-term physical health conditions

Adapted from Parry-Jones 2009

What does the guidance say?

There are a number of national documents with recommendations about psychological care for people living with diabetes:

The *Diabetes Delivery Plan for Wales 2016-2020* (Welsh Government 2016, p10), in a section on "Delivering Fast Effective Diabetes Care", states:

Assessment of psychological difficulties that may pose a barrier to effective self-care and medical management of diabetes is essential. Health boards must ensure sufficient psychological input into the management of patients in line with national standards. All members of the care team should be supported to provide an element of psychological support, in line with the pyramid of psychological need (Mental Health Network, NHS Confederation 2012), to target clinical psychologist support at those with the greatest need.

The *All-Wales Standard for People with Diabetes Moving from Paediatric to Adult Services within NHS Wales*, published in November 2017, specifies that:

Health boards should ensure specialist clinical psychology services are offered as a standard part of support services and clinical appointments, with dedicated clinical psychology posts embedded in the paediatric and adult diabetes teams and involved in the transition process. (Recommendation 3: p.10) and *Health boards should be aware of the increased risk of eating disorders, insulin omission and disordered eating and validated screening tools should be used alongside additional staff training and supervision by a psychology professional.* (Recommendation 4: p.11)

The *Well-being of Future Generations (Wales) Act 2015* sets a well-being duty on public bodies, including health boards, to carry out sustainable development and publish well-being objectives in line with seven well-being goals. The well-being goal, "A healthier Wales", aims to develop a society in which people's physical and mental well-being is maximised and that choices and behaviours are understood to benefit future health. Another well-being goal, "A more equal Wales", aims to promote a society that, no matter what their circumstances or background, enables people to fulfil their potential. Given the clear evidence that socioeconomic deprivation adversely impacts psychological health, we cannot provide equality in diabetes care without addressing psychological needs, particularly of people living in poverty. Without a lifespan approach to psychological care in this chronic condition, people with diabetes now, and those who have yet to develop it (or who could be prevented from developing it), will not be able to have their physical and mental health "maximised" nor be able to "fulfil their potential".

The *A Healthier Wales Policy* (2019) sets out a quadruple aim including *Improved population health and wellbeing* that facilitates better prevention and self-management: access to psychological support for this vulnerable population is key to ensuring effective self-management and prevention of both psychological and physical issues long-term. The policy also sets out a whole system value of *Proactively supporting people throughout the whole of their lives, and through the whole of Wales, making an extra effort to reach those most in need to help reduce the health and wellbeing inequalities that exist.* This aim strongly supports the need for embedded psychological care, where early intervention is key to reduce health deterioration and increasing costs to the NHS.

The *NICE guidance on Type 1 Diabetes for Adults* (2015) cites evidence that psychological factors, particularly mood, depression and injection anxiety, are associated with poor glycaemic control, and that there is a high prevalence of depression. The NICE guidance on Type 2 Diabetes (2008) cites evidence of, *a high prevalence of psychological ill-health in people with diabetes, notably for depression, which is often under-recognised.*

The *National Service Framework for Diabetes* (Department of Health 2002, p22) states:

The provision of information, education and psychological support that facilitates self-management is [ ] the cornerstone of diabetes care.

Other reports and guidelines from third sector agencies also provide strong evidence of the need for specialist diabetes psychology care provision (*e.g. Minding the Gap*, Diabetes UK 2008; *Emotional and Psychological Support and Care in Diabetes*, NHS Diabetes & Diabetes UK 2008; *The Future of Diabetes*, Diabetes UK 2017; *Too Often Missing: Making Emotional and Psychological Support Routine in Diabetes Care*, Diabetes UK 2019).

Purpose and scope of this document

This document is designed to meet four primary aims:

1. To provide a brief overview of the psychological issues that people living with diabetes routinely face, and the levels of difficulty that these issues can cause
2. To provide diabetes services with a framework for integrating existing psychological techniques, knowledge and resources into the delivery of routine diabetes care
3. To provide health boards and services with information and guidance that can be used to inform the development and ongoing management of specialist diabetes psychology services for adults
4. To provide health boards and services with examples of pathways and protocols to support PLWD with specific psychological needs

How was this document developed?

This document was primarily written by a Consultant Clinical Psychologist working in diabetes services, in consultation with the wider Welsh Adult Diabetes Psychology Network, and the UK Diabetes Psychology Network. Versions of the document have been circulated to patient groups and all-Wales reference groups for comments.

How should psychological care be delivered?

We believe that psychological care for PLWD should be delivered in a way that is *integrated, accessible, and flexible.*

- **Integrated –** people living with diabetes consistently report that they would prefer to access psychological support for their diabetes from within their diabetes teams (Diabetes UK, 2019). As such, psychological care should be embedded into diabetes teams and considered a core part of routine diabetes care. This involves building psychological awareness throughout the diabetes care system, training diabetes HCPs to be aware of, assess for, and offer basic support for psychological issues, and crucially, embed senior psychological practitioners within diabetes teams. This will enable diabetes HCPs to develop their psychological skills safely, and for psychology HCPs to develop their diabetes knowledge. The importance of functional integration of psychological practitioners within physical health services has been repeatedly identified as a priority area (The Kings Fund, 2016; The Psychological Professions Network, 2020). Integration allows for bilateral staff upskilling and development of more holistic services, and, crucially for PLWD, provides an easy to access and more cohesive service where psychological care is seen as the norm – this is consistently identified by PWLD as their preferred model of care (Joensen, 2019). Integrated care can be particularly effective for populations that services traditionally struggle to engage, such as young adults, individuals with T1DE (Partridge, 2020), or those with multiple psychological and social needs (Ismail, 2020) where distress is often high but individuals struggle to attend appointments.
- **Accessible –** people accessing psychological care need to be seen quickly, in a location and format that works for them. Diabetes psychology services need to be adequately staffed to avoid significant waiting lists; this is particularly important in young adult services where the ability to offer crisis diversion and support is essential. Workforce recommendations for diabetes psychology services are provided later in this document. PLWD should be able to access psychological support within their diabetes centres or the community, in suitable therapeutic spaces. Online therapy appointments should also be offered as an option to increase accessibility. Guided self-help resources should be well publicised, easily accessible and available in a range of formats and languages.
- **Flexible –** the range of psychological presentations in the population of PLWD is as diverse as the people themselves. Factors such as adverse childhood events, duration of diabetes, experience of diagnosis, life events and enduring stressors will all impact on a person's psychological health and presenting issues, and the impact these issues have on a person's diabetes management will also vary significantly. In addition, the impact of many other psychological, neurodevelopmental, cognitive and social issues (e.g. learning difficulties, substance misuse) can be significantly complicated by the added continual burden and complexity of diabetes, and individuals with both these issues and diabetes often require a significant level of additional support. Psychological practitioners should be sufficiently trained to offer a range of evidence-based therapies that can be individualised to a person's needs. Support for young adults should be as flexible as possible, avoiding the use of cancellation/DNA policies, and employing a range of communication strategies (e.g. email, text, web-based communication) to keep high risk individuals engaged.

A stepped-care model of psychological distress and care for people living with diabetes

As with other psychological issues, emotional distress in people living with diabetes can be viewed on a spectrum of severity – ranging from mild distress that has minimal impact on diabetes management and requiring little-no specialist support, to severe and high risk issues that completely compromise diabetes management, requiring significant input and management from multiple professionals and agencies working as a team. The level of need on the model is determined by the level of distress, and the impact of the distress on a person's diabetes management and general quality of life, rather than particular diagnostic categories or labels. The size of the step relates to the size of the population that will experience the issues and benefit from the intervention. By investing in preventative and early intervention measures and then matching levels of care to levels of need, it can be ensured that resources are used effectively and prudently, and that people are able to access support more easily. Each step on the pyramid is designed to be fluid, with practitioners working at steps 3 and 4 providing supervision, consultation and training to those delivering step 1 and 2 interventions. This is essential to ensure that staff working at steps 1 and 2 are both competent and confident in their work.

Steps 0-2 can be achieved by ensuring the current diabetes multi-disciplinary workforce has the correct training, resources and supervision to provide the recommended strategies, in the context of effective screening programmes and good consultation practice to ensure distress is identified as soon as possible. Steps 3-4 require staff with specialist knowledge of both diabetes and psychological issues, and multi-agency working. It is only by delivering care at *all* levels of the stepped-care model that we can truly support the psychological needs of all people living with diabetes in Wales.

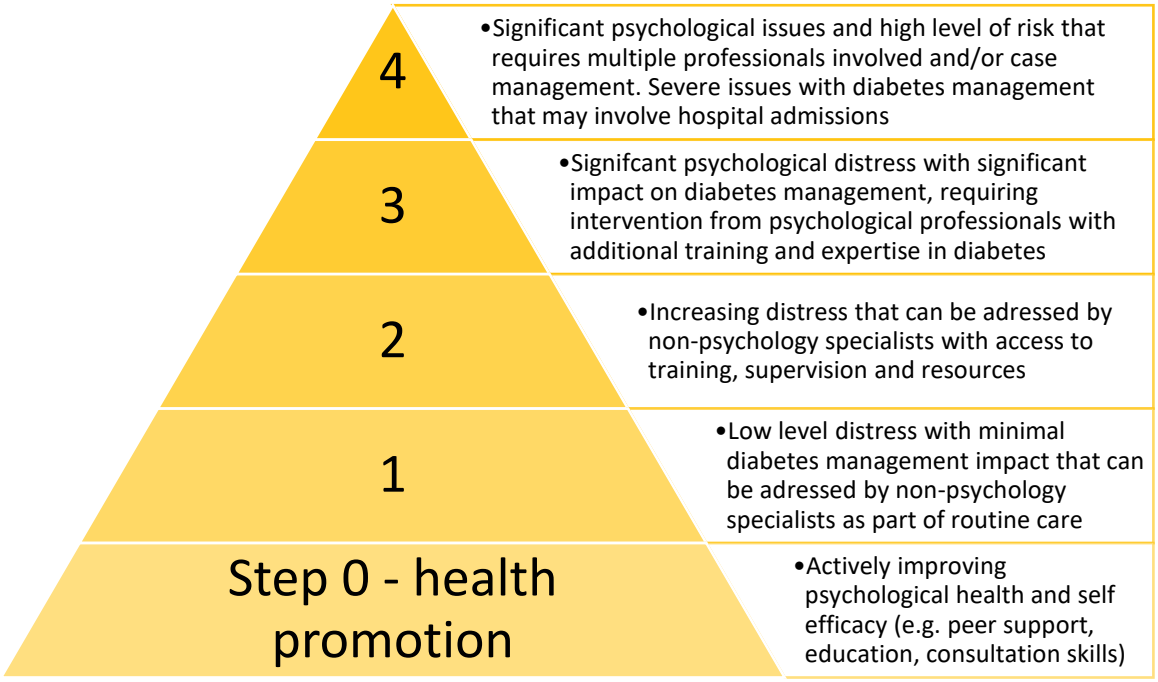


Figure 2 – Stepped-care model of psychological distress and care for people living with diabetes

Detailed information on the service activities undertaken at each point of the stepped-care model is provided in the next section.

Supporting diabetes services to deliver psychologically informed care

Step 0: Promoting psychological health in people living with diabetes

A crucial element of this version of the stepped-care pyramid is Step 0 – psychological health promotion. Given the burdens that PLWD face on a daily basis it is crucial that the health system recognises the importance of actively promoting and supporting activities that can bolster an individual's psychological health, and minimises any potential psychological harms that PLWD may face as a result of interacting with the healthcare system. This can be achieved in a number of ways:

- **Diabetes community -** Providing regular opportunities to access group education and peer support can help to boost psychological wellbeing at a population level and prevent development of psychological distress (Liu, 2020). Teams should make efforts to stay up-to-date with community based and 3rd sector support groups (e.g. via the dewis.wales site), helplines, websites and resources that PLWD may be able to access. In addition, teams should be encouraged and supported to put on additional meetings/events that PLWD can attend in order to meet other PLWD and update their diabetes knowledge.
- **Language matters -** The language used in diabetes appointments and associated communications can play an extremely important role, and has the power to boost and motivate PLWD, or conversely leave them feeling defeated and a 'failure'. All staff working in diabetes departments should be aware of the Language Matters (NHS England, 2018) standards, and communications coming from diabetes services should all be in line with the recommendations.
- **Personalised care -** All PLWD should receive care from the diabetes team that is responsive to their needs and personal priorities. Diabetes teams should employ a collaborative agenda setting approach with PLWD for every clinical contact, to ensure that PLWD receive individualised care that genuinely meets their needs. PLWD should be able to access care at a time, and in a format, that suits their needs and abilities, and should be supported by teams to discuss and access diabetes technology where applicable to their diabetes management needs.
- **Protect vulnerable groups -** Diabetes services should provide enhanced services for high-risk populations, such as young adults who are moving from paediatric to adult services. Fully implementing the guidance within the All-Wales standard (NHS Wales, 2017), including the recommendations for joint diabetes/psychology clinics for this vulnerable group, can help to ensure a safe transfer of care with minimal disruption and distress.
- **PLWD involvement -** seeking feedback from PLWD who use services is a routine part of care, however there are significant differences between seeking feedback and genuine co-production. Involving PLWD in service design, development and evaluation is essential to ensure that services deliver quality care and are not inadvertently causing potential harms (e.g. by causing the PLWD undue stress or anxiety). Guidelines on best practice and service user involvement have recently been published in Wales (Wales Mental Health and Wellbeing Forum, 2021), as has specific guidance on involving PLWD in improvement champion activity (Stewart, (In Press)); these and related guidance should be familiar to and frequently used by diabetes teams. Collecting Patient Reported Experience Measures should be a routine part of care, as should regular consultation with PLWD groups. Information should be provided to PLWD on how they can become more involved with service development work (e.g. patient advocacy roles), and training should be provided to ensure confidence and competence in these roles. It is particularly important for services to seek

feedback and involvement from those in groups that are often less heard in services (e.g. young adults, working age adults and people from ethnic minority backgrounds).

- **Systems thinking -** it is essential that psychological professionals are included in strategic planning and service development meetings for diabetes on a national and local level, to ensure that psychological thinking and the psychological needs of people living with diabetes become an integrated aspect of care planning and service development. This is essential not only to ensure that psychological wellbeing is considered and optimized at all points within the diabetes care system, but also to ensure that medicines management and NHS costs are positively impacted through the application of psychological thinking to systems design and delivery.
- **HCP awareness -** Psychological health for PLWD needs to be incorporated as a core element of training for HCPs working in diabetes. There are a number of online training modules that staff in Wales can access for free (e.g. Diabetes UK Emotional Wellbeing online module, CDEP training programme), and completion of this training should be considered to be equally as important as other areas of core diabetes training. Psychological awareness and training for HCPs can also play a positive role in mitigating staff burnout and sickness absence by supporting staff wellbeing; this is particularly important in the context of a stretched NHS workforce and the ongoing demands posed by the COVID pandemic.
- **Educational opportunities -** Education is a cornerstone of supported self-management in diabetes, yet while many PLWD are able to access education on aspects of diabetes management such as carbohydrate counting and interpreting blood glucose monitoring data, very few people in Wales are able to access information and strategies to support their psychological wellbeing. It is recommended that content on psychosocial aspects of living with diabetes is integrated into all standard education courses for PLWD, in a similar style to the successful approach adopted by the SEREN Connect course for young adults (see text box). Similarly, any general informational sources such as websites, apps and paper booklets should have psychological information incorporated into them as standard. This approach will maximise distress prevention opportunities and improved wellbeing for all PLWD who access education.

Good practice - SEREN Connect

The multi award winning SEREN Connect education programme for young people with diabetes moving from paediatric to adult diabetes services integrates psychological knowledge throughout the programme. Psychologists were involved in every stage of the programme development, which, as a result, includes elements of motivational interviewing, acceptance and commitment therapy and enhanced engagement techniques.

Step 1: Identifying issues and delivering basic support

Upskilling the existing diabetes workforce - Given the wide prevalence of psychological distress in people living with diabetes, it is essential that diabetes teams are upskilled and given sufficient training and resources to be able to identify, assess and take steps towards management of psychological distress in the people with diabetes that they support. The 7As model outlined in the Diabetes and Emotional Health Guide (Diabetes UK, 2019) provides a comprehensive framework for assessment and addressing of common psychological issues that PLWD face. Adopting this model on a national level is likely to reap significant benefits in the early identification and management of psychological distress. Given adequate training, time and support, it can reasonably expected that all specialist diabetes staff working in Wales can confidently deliver this model within their routine consultations, and deliver effective support for people experiencing a range of mild diabetes-related issues including diabetes distress, diabetes burnout, fear of hypoglycemia and needle phobia.

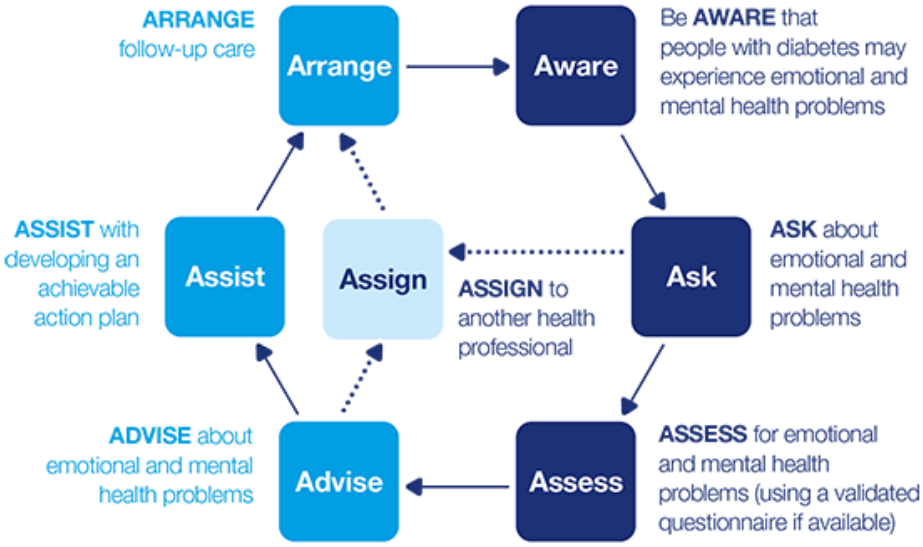


Figure 3 – 7As model (Diabetes UK, 2019)

Screening - A potential avenue for services to explore is that of routine psychological screening of PLWD at their diabetes clinic appointments, which can be particularly useful in high-risk groups such as young adults. Effectively managed screening programmes can quickly identify issues, and communicate to PLWD that their psychological health is an important component of their overall care. Particular issues to screen for include diabetes distress, low mood, and disordered eating; this is particularly important in people living with type 1 diabetes. Examples of validated screening questionnaires currently in use in services in Wales are provided in appendix 1 *(N.B the Welsh language versions of these measures are not currently validated)*. It is recommended that screening measures are agreed upon at a national level to facilitate inclusion within national audits and service evaluation.

Step 2: Psychological interventions for non-psychologists

If psychological distress has been identified that is not severe or putting the PLWD at significant risk, non-psychology members of the diabetes MDT have many of the competencies required to deliver step 2 psychological support, **providing that they have access to adequate training, resources and ongoing supervision/consultation.** Examples of step 2 interventions could include:

- Using guided self-help resources to provide an intervention for needle phobia or diabetes burnout
- Assessing and supporting a PLWD at risk of Type 1 Disordered Eating (T1DE) with the support of a local T1DE consultation group
- Using motivational interviewing to work with psychological insulin resistance

Where individual staff members have undertaken further training in psychological therapies (e.g. Cognitive Behavioural Therapy, or Acceptance & Commitment Therapy), and are able to access regular clinical supervision from a qualified psychological professional, it may be appropriate for more advanced interventions to be offered (e.g. a brief CBT intervention). However it is essential that staff work within their capabilities, and that adequate clinical supervision and caseload management is provided on a regular basis from a senior qualified psychological practitioner. An explanation of types of support that members of the diabetes MDT can access from their psychology colleagues is provided in table 1.

What is psychological training?	What is consultation?	What is supervision?
Non-psychologists can access a range of training via their local psychology colleagues. Examples include: • Engagement and active listening skills training • Training on specific techniques (e.g. motivational interviewing) • Training to deal with difficult situations (e.g. assessing risk) • Training on psychological or cognitive issues (e.g. eating disorders) • Introductory training to a range of therapies	Many psychologists offer consultation slots, where team members can bring cases or situations for discussion and advice. This can provide the consultee with new ideas and understanding, and can also reduce the risk of inappropriate referrals.	Supervision is a key component of the psychologist's role, to support team wellbeing and ensure client welfare. Supervision may occur formally or informally, in groups or on an individual basis. Content of supervision sessions may include discussing difficult cases, issues in the department, or building psychological awareness and engagement skills.

Table 1 – Forms of MDT support provided by psychologists working in physical health settings

Tools to use - Talking Type 1

The Talking Type 1 book range was developed in order to meet some of the unmet psychological need for people living with diabetes. Any professional with a relationship with the PLWD should be able to provide the support alongside the book. Each book has been written by a specialist diabetes psychologist, in conjunction with individuals who have lived experience of coping with, and recovering from each of the issues covered. Topics covered by the range include diabetes burnout, needle phobia, parent/carer distress and adjustment to diagnosis. By giving people access to these resources at an early stage, it is possible to reduce or entirely address distress before significant psychological or physical harm occurs.

Developing a psychology workforce to meet the needs of people with diabetes

Step 3: Specialist Diabetes Psychology support

As outlined earlier in this document, people living with diabetes can often present with complex psychological needs and significant levels of risk. Given this, it is important that psychological care is provided by a workforce with adequate training and expertise in working with high-risk individuals, delivering interventions that can be adapted to individual needs and holding senior/leadership roles within diabetes teams to ensure competence and credibility in providing supervision training and consultation. HCPC registration as a Practitioner Psychologist will be essential to work within NHS diabetes services, meaning that postholders will either be trained as Clinical, Counselling or Health Psychologists. Within Wales, the existing diabetes psychology posts in both adult and paediatric services are held predominantly by Clinical Psychologists.

Staffing levels - In a UK mapping exercise, the British Renal Society (British Renal Society, 2020) were able to identify published staffing ratios for practitioner psychologists working into a number of long-term physical health conditions. These are presented in table 2.

Area	Recommended staffing ratio	Notes
Cystic Fibrosis	1.0 WTE per 150 patients	Based on model that all CF patient require annual psychology input
Cancer	1.0 WTE per 600 patients	Based on stepped care model with specialist nurses delivering step 2
Renal (pre-dialysis)	1.0 WTE per 600 patients (minimum) 1.0 WTE per 375 patients (gold standard)	Based on stepped care model

Table 2 – Psychology staffing rations identified and recommended by the British Renal Association mapping exercise (British Renal Society, 2020)

Given that rates of psychological distress in people living with type 1 diabetes are similar to rates in people with renal disease, it is recommended that services provide a minimum staffing level of 1.0 WTE psychologists per 600 adults with type 1 diabetes, and aim for a gold standard staff level of 1.0 WTE psychologists per 375 adults with type 1 diabetes. Aiming for gold standard staffing would allow psychology staff to provide essential additional support in terms of service development, evaluation and audit, research and team support and training. Gold standard staffing would also allow for enhanced service provision for young adults. Additional staffing would need to be provided to support adults living with type 2 diabetes.

Level of staff seniority and training - given the specialist nature of their work and that most psychologists working in diabetes are sole practitioners within their teams, it is generally accepted that this role is unsuitable for newly qualified psychologists unless significant supervision from more experienced psychology colleagues is readily available. Most psychologists working in physical health settings work at band 8a level, unless they have management or service leadership responsibilities, in which case 8b or 8c banding is appropriate.

Management and governance of psychology roles - It is important when designing and commissioning psychology roles that consideration is given to adequate clinical supervision and support (this is a stipulation of HCPC registration for practitioner psychologists). Where clinical supervision and support from a senior diabetes psychologist cannot be sourced within a diabetes psychology or wider physical health psychology department, provision will need to be made for

funding of external supervision. Psychologists should also have protected time to engage in peer supervision, networking and specialist training with other diabetes psychologists to ensure continuing professional development and quality of service delivered.

Appendices 2-3 outline the routine roles and responsibilities of a psychologist working in adult diabetes services, and provide a framework for measuring service efficacy.

Step 4: Collaborative working for high risk individuals living with diabetes

Some individuals present with significant and potentially fatal risks because of their psychological needs. Suicidal intent has been consistently observed at a higher level in PLWD than in those without diabetes, and those who are prescribed insulin have near constant access to lethal drugs. It is a sad fact that the recorded number of PLWD who end their lives by suicide is likely to be significantly underestimated – not only are the statistics on suicide difficult to quantify in the general population (O'Connor, 2021), but many people with diabetes who have chosen to end their lives may have their cause of death recorded as another issues e.g. severe hypoglycaemia (Elamoshy, 2018). Furthermore, people with Type 1 Disordered Eating (T1DE) and/or repeat admissions for Diabetic Ketoacidosis are at significantly higher risk of early mortality. Where risk is a significant issue, it may often be necessary to refer PLWD to secondary care Adult Mental Health Services to ensure effective risk management and access to additional psychological and psychiatric treatments. However, in these cases it is essential that regular communication between services is established and maintained, and that risk assessments take diabetes management and access to potentially lethal medication into account. Managing care across multiple teams and systems can be challenging; it is therefore essential that clear, nationally agreed pathways for high-risk PLWD are developed and implemented.

Where a PLWD is receiving care from adult mental health services, risk assessments and Care and Treatment Plans should always incorporate an assessment of the potential for a person to neglect/self-harm by misusing their insulin, or, in the case of children and vulnerable adults, the risk of insulin being withheld or misused by others. The risk of a person deliberately overdosing using their insulin should always be assessed during routine mental health measure risk assessments. Specific risk assessments and care plans for insulin management may need to be considered and put in place for high risk individuals who are detained under the mental health act.

Many individuals with ongoing mental health issues are at higher risk of developing diabetes (e.g. through weight gain from anti-psychotic medication), yet consistently their physical healthcare needs are under recognised. Again, it is essential that diabetes teams and mental health teams form good working relationships in order to collaborate and support each other to deliver holistic healthcare for vulnerable individuals.

Managing support for high risk individuals with diabetes is stressful and it can take a significant toll on staff, particularly if they have known the person for a significant length of time. It is important the mental health and diabetes teams are able to share information and work together effectively, not just for the wellbeing of the PLWD, but also to allow mutual upskilling and support for the professionals involved. Where diabetes staff have been involved with a highly distressing situation involving a PLWD (e.g. a suicide attempt), they may benefit from being offered additional support by colleagues in psychology to avoid potential trauma and psychological injury.

Conclusion

Psychological support has been missing from diabetes services for too long, to the detriment of those living with diabetes, their families, and the care teams who support them. By fully embedding psychological thinking, training, support and supervision at all points within the diabetes care system we can start to address existing psychological need and ensure that opportunities to reduce distress and promote psychological wellbeing are maximized. While expanding or developing the diabetes psychology workforce will require investment, this investment will reap significant benefits to all people living with diabetes, and the NHS Wales healthcare system as a whole.

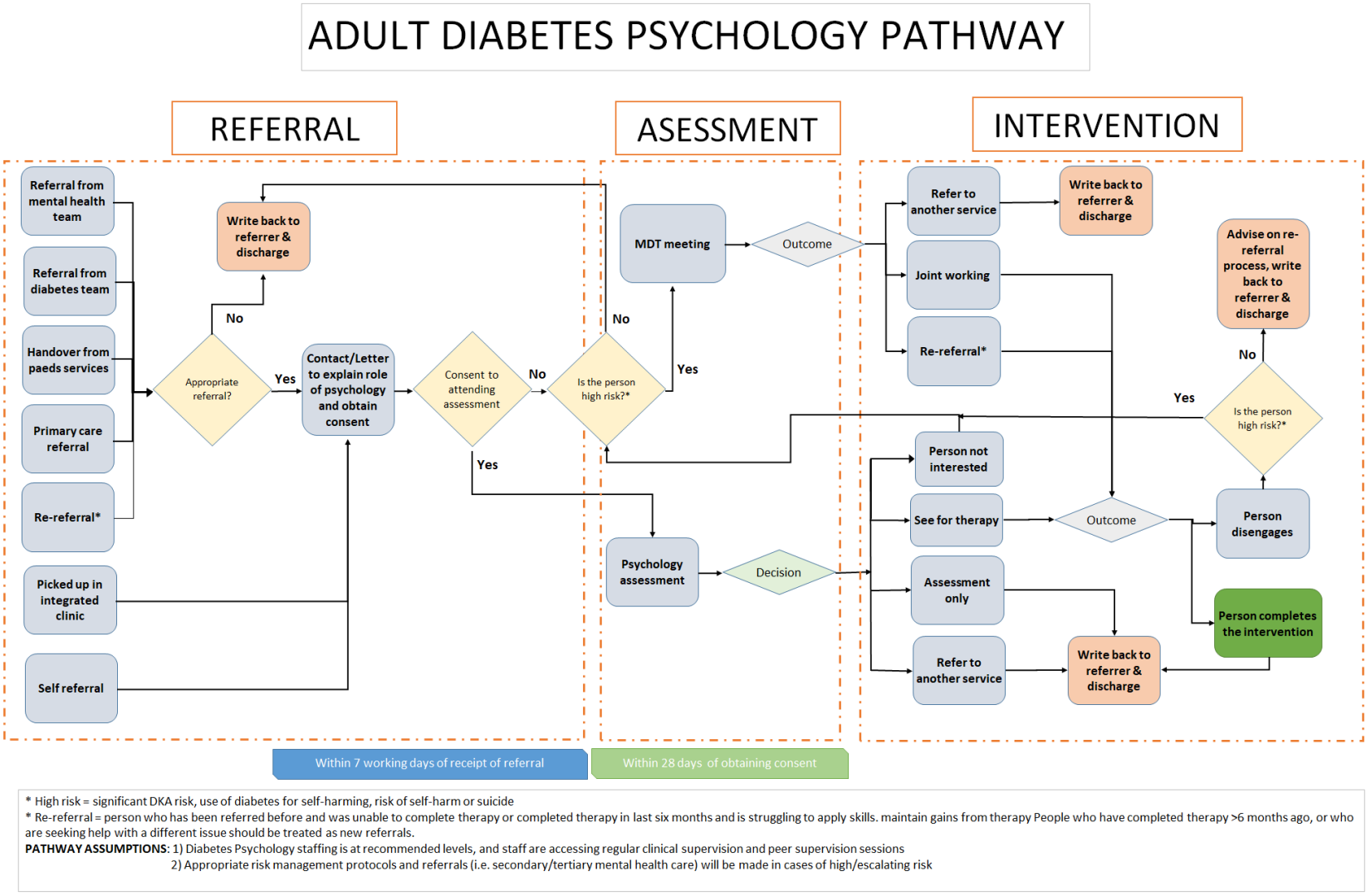
Pathways and protocols to support PLWD with specific psychological needs

Pathway 1: Psychological support for adults living with diabetes

Pathway 2: Psychological support for PLWD and repeated DKA admissions

Pathway 3: Psychological support for adults with Type 1 Disordered Eating (T1DE)

Pathway 1: Psychological support for adults living with diabetes



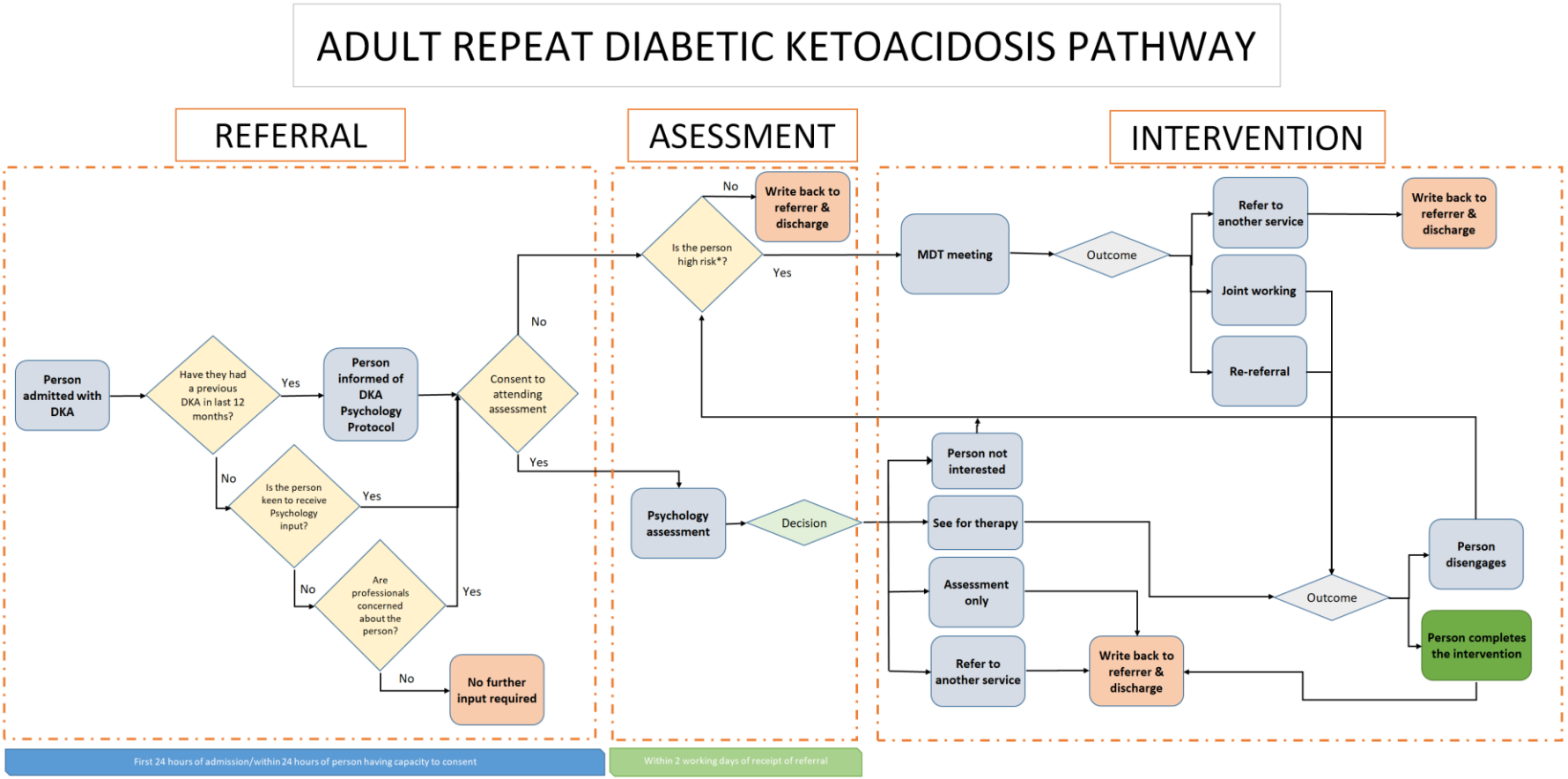
* High risk = significant DKA risk, use of diabetes for self-harming, risk of self-harm or suicide

* Re-referral = person who has been referred before and was unable to complete therapy or completed therapy in last six months and is struggling to apply skills. maintain gains from therapy People who have completed therapy >6 months ago, or who are seeking help with a different issue should be treated as new referrals.

PATHWAY ASSUMPTIONS: 1) Diabetes Psychology staffing is at recommended levels, and staff are accessing regular clinical supervision and peer supervision sessions

2) Appropriate risk management protocols and referrals (i.e. secondary/tertiary mental health care) will be made in cases of high/escalating risk

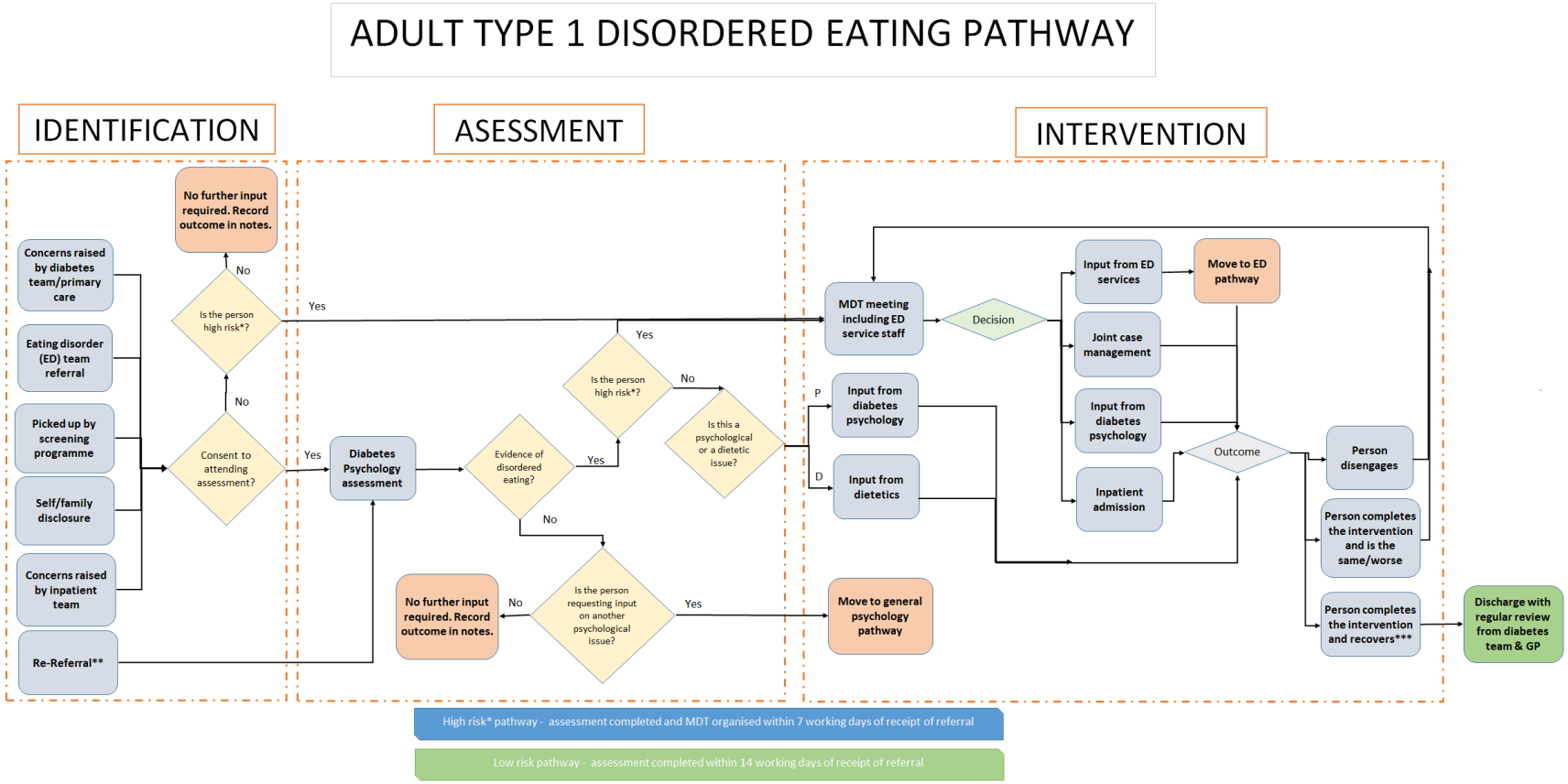
Pathway 2: Psychological support for PLWD and repeated DKA admissions



* High risk = significant DKA risk, use of diabetes for self-harming, risk of self-harm or suicide

PATHWAY ASSUMPTIONS: 1) Diabetes Psychology staffing is at recommended levels, and staff are accessing regular clinical supervision and peer supervision sessions
2) Appropriate risk management protocols and referrals (i.e. secondary/tertiary mental health care) will be made in cases of high/escalating risk

Pathway 3: Psychological support for adults with Type 1 Disordered Eating (T1DE)



* High risk = significant DKA or acute medical risk from malnourishment, use of diabetes for self-harming, risk of self-harm or suicide
** Re-referral = person who has been referred before and was unable to complete therapy or completed therapy in last six months and is struggling to apply skills. maintain gains from therapy People who have completed therapy >6 months ago, or who are seeking help with a different issue should be treated as new referrals.
*** Recovery defintied on an individaul basis, but should include sustained safe BMI & HbA1c/Time in range, and reduction in disordered eating behaviours and thought intrusion
PATHWAY ASSUMPTIONS: 1) Diabetes and ED staff are regularly attending local T1DE consultation groups and are up to date with T1DE treatment evidence base
2) Diabetes Psychology staffing is at recommended levels, and staff are accessing regular clinical supervision
3) Appropriate risk management protocols and referrals (i.e. secondary/tertiary mental health care) will be made in cases of high/escalating risk

References

Allcock, B. (. (2020). *From Repeat Diabetic Ketoacidosis to Expert by Experience: Exploring the Highs and Lows of Living with Type 1 Diabetes.* United Kingdom: Bangor University. Retrieved from https://research.bangor.ac.uk/portal/files/34949134/Allcock_thesis_20202020

British Renal Society. (2020). *A Multi-Professional Renal Workforce Plan for Adults and Children with Kidney Disease.*

Chatwin, H. B. (2021). The impact of hypoglycaemia on quality of life outcomes among adults with type 1 diabetes: A systematic review. *Diabetes Research and Clinical Practice, 174*, 108752. doi:https://doi.org/10.1016/j.diabres.2021.108752.

Diabetes UK. (2019). *diabetes and emotional health - a practical guide for healthcare professionals supporting adults with type 1 and type 2 diabetes.* London: Diabetes UK.

Diabetes UK. (2019). *Too Often Missing: Making emotional and psychological support routine in diabetes care.* London: Diabetes UK.

Elamoshy, R. B. (2018). Risk of depression and suicidality among diabetic patients: a systematic review and meta-analysis. *Journal of Clinical Medicine, 7*(11), 445. doi:https://10.3390/jcm7110445

Fisher, L. M. (2010). Diabetes distress but not clinical depression or depressive symptoms is associated with glycemic control in both cross-sectional and longitudinal analyses. *Diabetes Care, 33*(1), 23-28.

GIRFT - Getting It Right First Time. (2020). *Diabetes: GIRFT Programme National Speciality Report.* London: GIRFT. Retrieved from https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2020/11/GIRFT-diabetes-report.pdf

Hessler, D. M. (2017). Diabetes distress is linked with worsening diabetes management over time in adults with type 1 diabetes. *Diabetic Medicine, 34*(9), 1228-1234.

Ismail, K. S. (2020). A pilot study of an integrated mental health, social and medical model for diabetes care in an inner-city setting: Three Dimensions for Diabetes (3DFD). *Diabetic Medicine , 37*(10), 1658-1668. doi:https://doi.org/10.1111/dme.13918

Joensen, L. F. (2019). Integrating psychosocial support into routine diabetes care: perspectives from participants at the Self-Management Alliance meeting 2016. *Diabetic Medicine, 36*(7), 847-853.

Liu, F. G. (2020). Different Effects of Structured Education on Glycemic Control and Psychological Outcomes in Adolescent and Adult Patients with Type 1 Diabetes: A Systematic Review and Meta-Analysis. *International journal of endocrinology(9796019)*. doi:https://doi.org/10.1155/2020/9796019

Moussavi, S. C. (2007). Depression, chronic diseases, and decrements in health: results from the World Health Surveys. *The Lancet, 370*(9590), 851-858.

NHS England. (2018). *Language Matters: Language and diabetes.* NHS England.

NHS Wales. (2017). *All-Wales Standard for People with Diabetes Moving from Paediatric to Adult Services within NHS Wales.* Cardiff: NHS Wales.

O'Connor, R. (2021). *When it is Darkest: Why People Die by Suicide and What We Can Do to Prevent It.* London: Vermillion.

Partridge, H. F. (2020). Type 1 diabetes and disordered eating (T1DE): the ComPASSION Project–Wessex. *Practical Diabetes, 37*(4), 127-132. doi: https://doi.org/10.1002/pdi.2286

Polonsky, W. H. (2005). Assessing psychosocial distress in diabetes: development of the diabetes distress scale. *Diabetes Care, 28*(3), 626-631. doi:https://10.2337/diacare.28.3.62

Rotella, F. &. (2013). Diabetes mellitus as a risk factor for depression. A meta-analysis of longitudinal studies. . *Diabetes Res. Clin. Pract., 99*, 98–104. doi:https://10.1016/j.diabres.2012.11.022

Snoek, F. J. (2015). Constructs of depression and distress in diabetes: time for an appraisal. *The Lancet Diabetes & Endocrinology, 3*(6), 450-460. doi:https://10.1016/S2213-8587(15)00135-7

Stewart, R. A. ((In Press)). Developing opportunities for people with diabetes to engage in Improvement Champion activity: a practical guide for diabetes teams. *Practical Diabetes*.

The Kings Fund. (2016). *Bringing Together Physical and Mental Health: a new frontier for integrated care.* London: Kings Fund. Retrieved from https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Bringing-together-Kings-Fund-March-2016_1.pdf

The Psychological Professions Network. (2020). *Maximising the Impact of Psychological Practice in Physical Healthcare: Discussion Paper.*

Wales Mental Health and Wellbeing Forum. (2021). *Together Everyone Achieves More: Wales Guidance on Best Practice in Service User and Carer Engagement.*

Young-Hyman, D. D.-B. (2016). Psychosocial care for people with diabetes: a position statement of the American Diabetes Association. *Diabetes Care, 39*(12), 2126-2140.

Zheng, B. S.-A. (2021). Glycemic Control, Diabetic Complications, and Risk of Dementia in Patients With Diabetes: Results From a Large UK Cohort Study. *Diabetes Care, 44*(7), 1556-1563.

Appendix 1 – screening measures in use in Wales

17 item Diabetes Distress Scale (DDS17)

Living with diabetes can sometimes be tough. Listed below are 17 areas that people with diabetes sometimes have problems with. Please think about how much each of these areas have been a problem for you IN THE LAST MONTH and circle the number that feels right for you.

Please note that we're asking **how much** of a problem the areas have been for you, not just whether you've experienced them or not. So if a particular item happens but it's not a problem, you'd circle '1'. If it happens and it's a really big problem, you might circle '6'.

	Not a problem		Moderate problem		Really big problem	
1. Feeling that diabetes is taking up too much of my mental and physical energy every day	1	2	3	4	5	6
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care	1	2	3	4	5	6
3. Feeling angry, scared, and/or depressed when I think about living with diabetes	1	2	3	4	5	6
4. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes	1	2	3	4	5	6
5. Feeling that I am not testing my blood sugars frequently enough	1	2	3	4	5	6
6. Feeling that I am often failing with my diabetes routine	1	2	3	4	5	6
7. Feeling that friends or family are not supporting me with my diabetes (e.g. planning activities that conflict with my schedule, encouraging me to eat the 'wrong' foods)	1	2	3	4	5	6
8. Feeling that diabetes controls my life	1	2	3	4	5	6
9. Feeling that my doctor doesn't take my concerns seriously enough	1	2	3	4	5	6
10. Not feeling confident in my day-to-day ability to manage diabetes	1	2	3	4	5	6
11. Feeling that I will end up with serious long-term complications, no matter what I do	1	2	3	4	5	6

	Not a problem		Moderate problem		Really big problem	
12. Feeling that I am not sticking closely enough to a good meal plan	1	2	3	4	5	6
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be	1	2	3	4	5	6
14. Feeling overwhelmed by the demands of living with diabetes	1	2	3	4	5	6
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes	1	2	3	4	5	6
16. Not feeling motivated to keep up my diabetes self management	1	2	3	4	5	6
17. Feeling that friends or family don't give me the emotional support that I would like	1	2	3	4	5	6

Thanks for filling out the questionnaire. We'll use your answers to track how you're doing over time, and to help us make sure that we're giving you the best possible care.

Scoring (for clinician/office use only)

Scale	Sum items	Total	Divide by	New Total	Over 3?
Total	All		17		
Emotional	1, 3, 8, 11, 14		5		
Physician	2, 4, 9, 15		4		
Regimen	5, 6, 10, 12, 16		5		
Interpersonal	7, 13, 17		3		

Patient Health Questionnaire -9 items (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?

(Please circle your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
Column Totals				

Diabetes Eating Problem Scale-Revised (DEPS-R)

This form has 16 statements about food and diabetes. Please rate how often each statement applies to you using the following scale:

Never	Rarely	Sometimes	Often	Usually	Always
0	1	2	3	4	5

1. Losing weight is an important goal to me	0	1	2	3	4	5
2. I skip meals and/or snacks	0	1	2	3	4	5
3. Other people have told me that my eating is out of control	0	1	2	3	4	5
4. When I overeat, I don't take enough insulin to cover the food	0	1	2	3	4	5
5. I eat more when I am alone than when I am with others	0	1	2	3	4	5
6. I feel that it's difficult to lose weight and control my diabetes at the same time	0	1	2	3	4	5
7. I avoid checking my blood sugar when I feel like it is out of range	0	1	2	3	4	5
8. I make myself vomit	0	1	2	3	4	5
9. I try to keep my blood sugar high so that I will lose weight	0	1	2	3	4	5
10. I try to eat to the point of spilling ketones in my urine	0	1	2	3	4	5
11. I feel fat when I take all of my insulin	0	1	2	3	4	5
12. Other people tell me to take better care of my diabetes	0	1	2	3	4	5
13. After I overeat, I skip my next insulin dose	0	1	2	3	4	5
14. I feel that my eating is out of control	0	1	2	3	4	5
15. I alternate between eating very little and eating huge amounts	0	1	2	3	4	5
16. I would rather be thin than to have good control of my diabetes	0	1	2	3	4	5

Total Score

Appendix 2 - Components of the diabetes psychologist's role

Direct Clinical Work

Assessment

Diabetes psychologists offer specialist assessment considering biopsychosocial and treatment factors in the development and maintenance of presenting problems, working in inpatient and outpatient settings, with individuals and families. A range of assessment methods are used, including:

- Interviews and direct observation
- Psychometric tests
- Neuropsychological assessment (health/counselling psychologists require further training to undertake this)
- Risk assessment and risk management plans
- Assessment of mental capacity: particularly in relation to an individual's capacity to consent to medical treatment and to decide to withdraw from treatment
- Assessing need for referral of patients to mental health services and/or other relevant agencies.

Following assessment, diabetes psychologists develop a formulation, drawing on psychological theory and research, making sense of the interplay between psychological and physical well-being, providing several hypotheses and treatment options. Where appropriate, this can be shared with the multi-professional team to facilitate collaborative working, consistent team approaches and increased understanding.

Intervention

Based on the assessment, diabetes psychologists provide individually-tailored, evidence-based interventions/ management plans using a range of approaches including:

• Behavioural and cognitive behavioural techniques
• Mindfulness
• Compassion-Focused Therapy
• Acceptance and Commitment Therapy
• Motivational Interviewing
• Family Therapy
• Eye Movement Desensitisation and Reprocessing

Examples of interventions include:

• Supporting adjustment to diagnosis, management of distress and maximising quality of life
• Helping PLWD cope with the challenges of diabetes management and associated treatments/procedures, e.g. anxiety about hospitals and/or invasive procedures, symptom-management techniques, improving engagement and adherence with complex treatment regimes
• Psychological intervention for difficulties linked to diabetes e.g. diabetes distress, burnout, disordered eating, development of long-term diabetes complications, repeat DKA admissions
• Preparation and support for patients through transitions, e.g. child to adolescence to adult services
• Group-based interventions.

PLWD education

• Co-facilitate group education sessions for PLWD or support other professionals in the development of the content
• Assist with the development of written information for PLWD

Within their training, clinical psychologists specifically have experience and competencies of working across the lifespan, including people with learning disabilities and cognitive impairment. These skills can be applied in supporting the team where individuals in these groups require education.

Consultation and joint work

Diabetes psychologists can provide specialist psychological advice and guidance to diabetes teams through:

• Consultation (e.g. at ward rounds, diabetes clinical meetings)
• Planned joint patient work with other MDT professionals
• Clinical supervision (1:1 or group) to other diabetes team professionals
• Providing staff support and reflective practice opportunities on an on-going basis and in response to specific, difficult situations. This work helps to manage and reduce staff stress and promotes effective communication and teamwork amongst colleagues.

Education and support for diabetes staff

• Participation and delivery of training on psychological impact of diabetes, and diabetes specific psychological issues
• Emotional containment – clients and staff
• Supervision for other healthcare professionals
• Reflective practice groups, education, training and consultancy.

Audit, research, service evaluation and service and policy development

As scientist practitioners, this area is a core role in practitioner psychologist job descriptions. The diabetes psychologist has specialist skills and experience in conducting psychological research. This is applied to understanding psychosocial issues in diabetes and improving psychological care in diabetes services through developing individual projects or advising on/participating in research carried out by the MDT. The diabetes psychologist also brings specialist skills and experience in:

• Service evaluation
• Audit and service development
• Ensuring evidence-based and developmentally appropriate psychological approaches are embedded within policies, procedures and pathways in the department.

Supervision

- Diabetes psychologists have a responsibility to engage in continuing professional development (CPD) and supervision of their practice to maintain their Health and Care Professions Council (HCPC) registration
- Supervision is funded by the trust/employer and delivered in work time
- The amount of supervision will vary depending on the grade of a particular psychologist, however, this should be at a minimum of one hour per month for more senior staff, with increased frequency for those newly qualified.

Adapted from (British Renal Society, 2020)

Appendix 3 – example outcomes for a diabetes psychology service

Outcome	How it can be measured
Psychology sessions need to be acceptable to service users	• Session attendance rate • Service user feedback questionnaire
Psychology sessions need to be effective	• PROMS & problem specific measure scores • DKA rate & repeat DKA rate • Blood glucose monitoring & HbA1c/Time in range • Size of waiting list
Service needs to give fast access to particularly vulnerable patients	• Rapid DKA assessment/debrief (ideally inpatient) • Demonstrate enhanced efforts to engage people with repeat DKAs
Service needs to promote psychological wellbeing for all adults under the diabetes service	• Attending young adult clinic and transition clinics • Contribute to education days (e.g. 'meet the psychologist' sessions) • Contribute to and develop national and UK-wide groups, guidelines and projects for PLWD • Publishing papers
Service needs to strive to continually improve PLWD experience	• Develop good working relationships & meeting schedule with adult & paediatric teams • Look at developing & implementing new resources • Developing new ways to engage PLWD with the service (e.g. developing a service user forum)
Service needs to use psychology provision to upskill wider MDT and promote Health Psychology/Diabetes Psychology	• Teaching sessions (with attendee feedback) • Speaking at conferences • Publishing papers • Offering staff supervision & consultation (formal or informal) • Regularly sharing relevant journal articles and guidelines with MDT • Working with local training courses (teaching, supervising trainees)
Service needs to pilot & develop new processes for particularly vulnerable groups (specific project work)	• Developing new assessment frameworks • Developing resources for people with particular issues